

## Comparing results from long and short form versions of the Parkinson's disease questionnaire in a longitudinal study

Jenkinson, Crispin; Clarke, Carl; Gray, Richard; Hewitson, Paul; Ives, Natalie; Morley, David; Rick, Caroline; Wheatley, Keith; Williams, Adrian

DOI:

[10.1016/j.parkreldis.2015.09.008](https://doi.org/10.1016/j.parkreldis.2015.09.008)

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

*Document Version*

Peer reviewed version

*Citation for published version (Harvard):*

Jenkinson, C, Clarke, C, Gray, R, Hewitson, P, Ives, N, Morley, D, Rick, C, Wheatley, K & Williams, A 2015, 'Comparing results from long and short form versions of the Parkinson's disease questionnaire in a longitudinal study', *Parkinsonism and Related Disorders*, vol. 21, no. 11, pp. 1312-1316.  
<https://doi.org/10.1016/j.parkreldis.2015.09.008>

[Link to publication on Research at Birmingham portal](#)

### General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### Take down policy

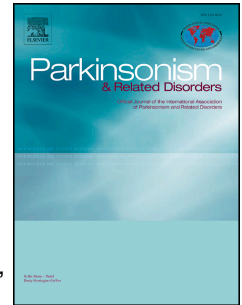
While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

# Accepted Manuscript

Comparing results from long and short form versions of the parkinson's disease questionnaire in a longitudinal study

Crispin Jenkinson, Professor, Carl Clarke, Richard Gray, Paul Hewitson, Natalie Ives, David Morley, Caroline Rick, Keith Wheatley, Adrian Williams



PII: S1353-8020(15)00383-1

DOI: [10.1016/j.parkreldis.2015.09.008](https://doi.org/10.1016/j.parkreldis.2015.09.008)

Reference: PRD 2767

To appear in: *Parkinsonism and Related Disorders*

Received Date: 18 April 2015

Revised Date: 20 August 2015

Accepted Date: 1 September 2015

Please cite this article as: Jenkinson C, Clarke C, Gray R, Hewitson P, Ives N, Morley D, Rick C, Wheatley K, Williams A, Comparing results from long and short form versions of the parkinson's disease questionnaire in a longitudinal study, *Parkinsonism and Related Disorders* (2015), doi: 10.1016/j.parkreldis.2015.09.008.

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

# COMPARING RESULTS FROM LONG AND SHORT FORM VERSIONS OF THE PARKINSON'S DISEASE QUESTIONNAIRE IN A LONGITUDINAL STUDY

Crispin Jenkinson<sup>1</sup>

Carl Clarke<sup>2</sup>

Richard Gray<sup>3</sup>

Paul Hewitson<sup>1</sup>

Natalie Ives<sup>4</sup>

David Morley<sup>1</sup>

Caroline Rick<sup>4</sup>

Keith Wheatley<sup>5</sup>

Adrian Williams<sup>6</sup>

<sup>1</sup> Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Oxford, UK.

<sup>2</sup> Department of Neurology, City Hospital, Sandwell and West Birmingham Hospitals NHS Trust, Birmingham, UK.

<sup>3</sup> Clinical Trial Service Unit, Nuffield Department of Population Health, University of Oxford, Oxford, UK.

<sup>4</sup> Birmingham Clinical Trials Unit, University of Birmingham, Birmingham, UK.

<sup>5</sup> Cancer Research UK Clinical Trials Unit, School of Cancer Studies, University of Birmingham, UK.

<sup>6</sup> Department of Neurology, University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK.

*\*Correspondence to Professor Jenkinson*

*Health Services Research Unit, Nuffield Department of Population Health, Rosemary Rue Building, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF, UK.*

*Email: [crispin.jenkinson@dph.ox.ac.uk](mailto:crispin.jenkinson@dph.ox.ac.uk)*

*Telephone: 01865 289441*

**Word count:** up to 3000 words exclusive of abstract, legends, and references

**Running title:** Parkinson's Disease Questionnaire

**Key words:** Parkinson's Disease Questionnaire, PDQ-39, PDQ-8, PDQ Single Index, Patient Reported Outcomes

**Financial Disclosure/Conflict of Interest concerning the research**

**related to the manuscript:** All information on support and financial issues from all authors relative to the research covered in the submitted manuscript must be disclosed regardless of date. Other financial information unrelated to the current research covering the past year will be documented at the end of the manuscript.

**Funding sources for study:** Data reported in this study were generated from PD MED, a randomised controlled trial funded by the NHS Health Technology Assessment programme. The views and opinions expressed in this article are those of the authors and do not necessarily reflect those of the HTA programme, NIHR, NHS or the Department of Health.

**Abstract**

**Background** - The purpose of this study was to determine the extent to which summary index scores from the short form Parkinson's Disease Questionnaire (PDQ-8) replicate those from the parent form (PDQ-39) in a longitudinal study.

**Methods** – Longitudinal data gained from the PD-MED trial were examined (n=1867), to determine the extent the PDQ-8 replicates results from the PDQ-39 at baseline and follow up. The sensitivity to change of the PDQ-8 was also compared with that of the PDQ-39. Finally, results on the two measures were compared with those from the Hoehn and Yahr (HY) clinical staging scale.

**Results** – Results of the Single Index summary score gained from the PDQ-8 were found to closely replicate those gained from the PDQ-39 at each of the three time points. Furthermore at each time point the intraclass correlation coefficient between the two measures was very high (ICC range 0.93 – 0.96). Similarly, the two measures gave very similar accounts of change (e.g. from baseline to follow up at one year effect sizes were 0.18 for the single index calculated using the PDQ-39, and 0.09 when calculated using the PDQ-8). Similar levels of correlation were found between the two indices when correlated with the HY scale.

**Conclusions** – The PDQ-8 closely replicates results gained from the PDQ-39 when calculating single indices. In instances where a single summary score of the impact of PD on self-reported quality of life is needed, it is likely the PDQ-8 will provide reliable and accurate information.

## Introduction

Patient reported outcome measures (PROs) play an increasingly important role in the evaluation of medical care [1] and have been advocated as potentially important end-points in clinical trials [2]. Traditionally, neurologists have chosen to develop rating scales for Parkinson's disease (PD) based on clinical assessment [3] and which classically focus on neurological symptoms and physical impairment [4,5,6,7]. However, typically such instruments fail to address the full impact of the illness upon subjectively assessed quality of life (QoL) of patients [8]. Consequently, a number of PD specific PROs have been developed [9] to capture the overall impact of PD on health-related quality of life with the most widely used and validated being the Parkinson's Disease Questionnaire (PDQ-39) [10,11,12]. Use of the instrument has been recommended in a number of critical reviews of competing PROs in PD [13,14,15].

The PDQ-39 is a 39 item self-report questionnaire which measures eight dimensions of health. The instrument was developed on the basis of interviews with people with Parkinson's (PwP) and consequently measures areas of concern which are of particular salience to this patient group. Furthermore, scores from the eight dimensions can be aggregated onto the same metric to provide a single index of the overall impact of PD on self-reported health status [16]. Such summary indices are useful in giving a

global score of the impact of disease, and are useful in trials by reducing the risk of chance findings due to multiple comparisons across dimensions [17].

Further research developed a shorter form PDQ which can be used to create the single index. The PDQ-8 [18] was developed by selecting the item from each dimension most highly correlated with the corrected dimension total. The resulting PDQ-8 summary index (PDQ-8-SI) has been shown to produce, in cross sectional and test-retest studies, results that are encouragingly similar to the PDQ-39 summary index (PDQ-39-SI) [19]. However, to date limited information has been available concerning the sensitivity to change of the PDQ-8 in relation to the PDQ-39 over time. This is an important issue when selecting and using instruments in evaluative studies [2]. Consequently, the aim of this study was to compare data generated from the PDQ-8-SI and the PDQ-39-SI over time, in a longitudinal study.

## Methods

Data reported here are from PD-MED, a randomised clinical trial evaluating the comparative clinical and cost-effectiveness of different classes of drugs in PwP. Patients were categorised as receiving treatment for 'either' early or 'late' PD. Those classified as 'late' were those whose symptoms were no longer controlled by their first class of treatment. The primary outcome measure for the trial was health-related QoL as measured by the PDQ-39. In this paper data is not broken down by treatment arm but is broken down by 'early'/'late' categories. Full details of the trial design and results are published elsewhere [20].

The trial was awarded Multi-Centre Research Ethics Committee (MREC) approval and Clinical Trials Authorisation from the Medicines and Healthcare Regulatory Authority (MHRA). All respondents gave informed written consent to participate in the study.

**Participants:** PwP from over 80 neurology and care of the elderly units across the United Kingdom participated in clinic-based tests and postal evaluations via questionnaires. PD MED recruited 2120 patients - 1620 early and 500 later patients. 1366 (64.4%) of PwP in PD MED were male and 754 (36.6%) female. In this study only participants who had complete data to enable calculation on the PDQ-8-SI and PDQ-39-SI are included in the analyses. Consequently, 1434 (88.51%) PD MED early and 433 (86.6%) late respondents are reported. The mean age at recruitment into the study was



70.46 years (range 27 to 94), and mean disease duration was 11.22 years (range 4.9 to 38.6 years).

**Materials.** Three validated measures form the basis of the analyses reported here:

- The PDQ-39 [11]: As previously introduced, a 39 item self-report questionnaire which measures eight dimensions of health, namely mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. Dimension scores are coded on a scale of 0 (perfect health as assessed by the measure) to 100 (worst health as assessed by the measure). A number of studies indicate that the instrument possesses sound levels of reliability, validity and responsiveness [10,11,12,21,22,23]. The PDQ-39-SI is calculated by summing the eight dimensions of the instrument and standardising the score on a scale of 0 to 100.
- The PDQ-8 [18]: As previously introduced, an 8 item self-report questionnaire derived from its parent questionnaire, the PDQ-39 [11]. The PDQ-8 has been shown to exhibit appropriate levels of reliability, validity and responsiveness [12,18,19]. The PDQ-8-SI is calculated by summing the eight items of the instrument and standardising the score on a scale of 0 to 100. It should be stressed that the PDQ-8 was not administered as a separate instrument in this study. Rather, it was calculated from PDQ-39 data which may have influenced the manner in which items were

completed. It is, however, standard practice to assess short form instruments in this way [18,24,25,26]. All PDQ data was collected by paper and pen completion via postal surveys.

- The modified Hoehn and Yahr (HY) staging scale [4, 27]: A widely used clinical measure of disability in PwP, the HY scale classifies seven stages of disease which are rated by a clinician. The scale is regarded as fulfilling reasonable criteria for reliability and validity [26]. All HY data was obtained in clinic visits.

**Statistical analysis.** Trial data from baseline and three follow up points (one, two and three years) were subject to analysis. The data are analysed broken down by 'early'/'late' category, but not analysed by treatment arm. Descriptive statistics (mean, standard deviation (SD), median, minimum, maximum) were calculated for the PDQ-39 and PDQ-8 single indices. Concordance between the two indices was evaluated by the intraclass correlation coefficient (ICC; two-way mixed average, absolute agreement) in conjunction with the calculation of 95% confidence intervals (CIs). Mean change scores were calculated for the summary index of the PDQ-39 and the PDQ-8. Effect sizes, i.e. change in score in relation to its SD [28] were also calculated for the summary index on both the PDQ-39 and PDQ-8. Scores on the two PDQ indices were correlated with the HY scale cross-sectionally, using Spearman's rho. Data was analysed using SPSS Version 19.

## Results

Tables 1 and 2 report scores on the PDQ-39-SI and the PDQ-8-SI, broken down by 'early' and 'late' PD respectively, for those respondents who completed all items on the PDQ-39 which enables calculation of the summary scores. No meaningful differences were found between scores on the PDQ-39-SI and the PDQ-8-SI at any of the time points. Indeed, mean differences between the two scores were very small, ranging from 0.6 to 1.1 points. ICCs suggested that the results for both 'early' and 'late' respondents from both measures were remarkably similar at each time point with ICCs ranging from 0.93 (95% CI 0.92 – 0.94) to 0.96 (95% CI 0.96 – 0.97). Change scores on the two versions of the PDQ were calculated and ICCs calculated between them and ranged from 0.89 (95% CIs 0.88 – 0.90) to 0.90 (95% CIs 0.89-0.91).

The sensitivity to change of the PDQ-8-SI was compared with that of the PDQ-39-SI. Mean change scores over time were found to be similar and found to be highly correlated (ICCs ranged from 0.89 to 0.90). Table 3 reports mean changes between baseline and follow up at one, two and three years. Effect sizes were also calculated, and indicate the PDQ-8-SI replicates the results of the parent form.

Scores from respondents assessed by a clinician on the Hoehn and Yahr scale (H&Y) are presented in Table 4. PDQ-39-SI and PDQ-8-SI scores were

correlated with this score at the three follow up points. Both versions of the PDQ correlated moderately, and, importantly, reflected similar levels of magnitude, with the H&Y scale at all follow up time points. At year one the H&Y correlation with the PDQ-39-SI was 0.27,  $n=1551$ ,  $p<0.001$  and, for the PDQ-8-SI it was  $\rho=0.26$ ,  $n=1551$ ,  $p<0.001$ , at year two the correlations were  $\rho=0.31$ ,  $n=1442$ ,  $p<0.001$  and  $0.33$ ,  $n=1442$ ,  $p<0.001$  respectively, and at year 3 the correlations were  $\rho=0.33$ ,  $n=1181$ ,  $p<0.001$  and  $0.32$ ,  $n=1181$ ,  $p<0.001$  respectively.

## Discussion

Previously reported research using higher order factor analyses of the eight domains of the PDQ-39 across countries supports the derivation of the PDQ-39-SI and PDQ-8-SI [19,29]. In the current study comparison is made of the two summary indices in order to investigate how closely they replicate one another. Data reported from PD-MED is for baseline and follow up at one, two and three years, which provide sufficient data to assess the operating characteristics of both indices cross-sectionally and over time.

Mean and median scores for the two measures were strikingly similar. Results, when broken down by PD 'Early' or 'Late' indicated that the operating characteristics of the measures were consistent. Thus, PDQ-8-SI scores were highly significantly correlated with those of the PDQ-39-SI for both 'early' and 'late' respondents'. The two instruments also provided remarkably similar

pictures of change over time. The construct validity of the two measures was assessed by comparing results with a clinical assessment of disease status. Correlations between the two index scores and the HY scale were virtually identical.

The results presented suggest that the PDQ-8 can replicate results gained from the PDQ-39 for the single index score. It can do this with considerable economy, in terms of time needed to complete, and with considerable accuracy at the level of the group. Such results might be of significant interest where a brief measure is required due to time constraints or concerns regarding respondent burden, something of particular concern when assessing those in the more advanced stages of PD. Where this is the case investigators can, with confidence, incorporate the PDQ-8 as a means of capturing the impact of PD over time in, for example, clinical trials. It must be stressed, however, that where a detailed profile of disease impact on different dimensions is required the PDQ-39 should remain the instrument of choice.

Copies of the instruments, and a user manual, are available from the authors.

**Acknowledgment(s):** We wish to thank all of the respondents who graciously gave of their time to take part in this study. We also thank all the neurosciences team at BCTU for all their work on the PD MED trial that contributed the data to these analyses, in particular Francis Dowling, Ryan Ottridge and Smitaa Patel.

**Author Roles:** AW, RG, CC, NI, KW, CR, CJ designed the study. Statistical analysis was undertaken by CJ, PH, DM. First draft of the manuscript by CJ, DM and PH. All authors reviewed and commented on the final manuscript.

**Conflict of interest:** CJ is an author of PDQ-39 and has received royalties for its use in commercially funded studies. He has also acted as a consultant for Oxford University Consulting. CC has received honoraria for lectures, travel expenses for conferences and unrestricted educational grants from Abbott, Boehringer-Ingelheim, GlaxoSmithKline, Orion Pharma, Novartis, Teva and UCB. The remaining authors declare no potential conflicts of interest.

1. J. Dawson, H. Doll, R. Fitzpatrick, C. Jenkinson, A. Carr, The routine use of patient reported outcome measures (PROMs) in healthcare settings, *BMJ*. 340 (2010) 464-467.
2. Food & Drug Administration, Department of Health and Human Sciences: Guidance to Industry. Patient Reported Outcome Measures. Use in Medical Product Development to Support Labelling Claims, Food and Drug Administration, Silver Spring, Maryland, 2009.
3. J.M.S. Diamond, C.H Markham, Evaluating the evaluations: or how to weigh the scales of Parkinsonian disability, *Neurology* 33 (1983) 1098-1099.
4. M. Hoehn, M. Yahr, Parkinsonism: onset, progression and mortality. *Neurology* 17 (1967) 427-442.
5. M.A. Hely, T. Chey, A. Wilson, P.M. Williamson, D.J. O'Sullivan, D. Rail, J.G. Morris, Reliability of the Columbia Scale for Assessing Signs of Parkinson's Disease, *Mov Disord*. 8 (1993) 466-472.
6. S. Fahn, R.L. Elton, and members of the UPDRS development committee. Unified Parkinson's Disease Rating Scale, in: S. Fahn, M. Marsden, M. Goldstein, D.B. Calne (Eds.), *Recent Developments in Parkinson's Disease*, Volume 2. Macmillan, New York, 1987, pp. 153-163.
7. R.S. Schwab, A.C. England, Projection technique for evaluating surgery in Parkinson's disease, in: F.J. Gillingham, M.C. Donaldson (Eds.), *Third Symposium of Parkinson's Disease*, Livingstone, Edinburgh, 1969, pp. 152-157.
8. W.T. Longstreth, L. Nelson, M. Linde, D. Munoz, Utility of the Sickness Impact Profile in Parkinson's disease, *J. Geriatr. Psychiatry Neurol*. 5 (1992) 142- 148.
9. C. Jenkinson, R. Fitzpatrick, The development and validation of the Parkinson's Disease Questionnaire and related measures, in C. Jenkinson, M. Peters, M. Bromberg (Eds). *Quality of Life Measurement in Neurodegenerative and Related Conditions*, Cambridge University Press, Cambridge, 2011, pp 10-23.
10. C. Jenkinson, V. Peto, R. Fitzpatrick, R. Greenhall, Self-reported Functioning and Well-being in Patients with Parkinson's Disease: Comparison of the Short-form Health Survey (SF-36) and the Parkinson's Disease Questionnaire (PDQ-39), *Age Ageing* 24 (1995) 505-509.

11. V. Peto, C. Jenkinson, R. Fitzpatrick, R. Greenhall, The development and validation of a short measure of functioning and well being for individuals with Parkinson's disease, *Qual Life Res.* 4 (1995) 241-248.
12. C. Jenkinson, R. Fitzpatrick, V. Peto, S. Dummett, D. Morley, P. Saunders, The Parkinson's Disease Questionnaires User Manual, Third Edition. Health Services Research Unit, Oxford, 2012.
13. A.M. Damiano, C. Snyder, B. Strausser, M. Willian, A review of health-related quality-of-life concepts and measures for Parkinson's disease. *Qual Life Res.* 8 (1999) 235-243.
14. B.L. Den Oudsten, G.L. Van Heck, J. De Vries J, The suitability of patient-based measures in the field of Parkinson's disease, *Mov Disord.* 22 (2007) 1390-2401.
15. P. Martinez-Martin, M. Jeukens-Visser M, K. Lyons, C. Rodriguez-Blazquez, C. Selai, A. Siderowf, M. Welsh, W. Poewe, O. Rascol, C. Sampaio, G. Stebbins, C. Goetz, A Schrag, Health related quality of life scales in Parkinson's disease: Critique and recommendations, *Mov Disord.* 26 (2011) 2371-2380.
16. C. Jenkinson, R. Fitzpatrick, V. Peto, R. Greenhall, N. Hyman, The PDQ-39: Development of a Parkinson's Disease summary index score, *Age Ageing* 26 (1997) 353-357.
17. J.E. Ware, M. Kosinski, S. Keller, SF-36 Physical and Mental Summary A User's Manual, The Health Institute, New England Medical Center, Boston, Massachusetts, 1994.
18. C. Jenkinson, R. Fitzpatrick., V. Peto, R. Greenhall, N. Hyman, The PDQ-8: Development and validation of a short-form Parkinson's disease questionnaire, *Psychol Health* 12 (1997) 805-814.
19. C. Jenkinson, R. Fitzpatrick, Cross cultural evaluation of the short form 8 item Parkinson's Disease Questionnaire (PDQ-8): Results from America, Canada, Japan, Italy and Spain, *Parkinsonism Related Disord.* 13 (2007) 22-28.
20. PD Med Collaborative Group, Long-term effectiveness of dopamine agonists and monoamine oxidase B inhibitors with levodopa as initial treatment for Parkinson's disease (PD MED): a large, open-label, pragmatic randomised trial, *Lancet* 384 (2014) 1196-1205.
21. V. Peto, C. Jenkinson, R. Fitzpatrick, PDQ-39: a review of the development, validation and application of a Parkinson's disease quality of



- life questionnaire and its associated measures, *J Neurol.* 245 Suppl 1 (1998) S10-14.
22. R. Fitzpatrick, C. Jenkinson, V. Peto, N. Hyman, R. Greenhall, Desirable properties for instruments assessing quality of life: evidence from the PDQ-39, *J Neurol Neurosurg Psychiatr.* 62 (1997) 104.
23. Peto V, Jenkinson C, Fitzpatrick R. Determining minimally important differences for the Parkinson's Disease Questionnaire (PDQ-39), *Age Ageing* 2001;30: 299-302.
24. J.E. Ware, M. Kosinski, M.S. Bayliss, C. McHorney, W.H. Rogers, A. Raczek, Comparison of methods for scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study, *Med Care* 33 Supplement (1995) AS264-279.
25. D. Morley, S. Dummett, L. Kelly, M. Peters, J. Dawson, R. Fitzpatrick, C. Jenkinson, The PDQ-Carer: Development and validation of a summary index score, *Parkinsonism Related Disord.* 19 (2013) 448-449.
26. D. Morley, C. Jenkinson, H. Doll, G. Lavis, R. Sharp, P. Cooke, J. Dawson, The Manchester-Oxford Foot Questionnaire (MOXFQ): Development and validation of a summary index score, *Bone Joint Res.* 2 (2013) 66-69.
27. C.G. Goetz, W. Poewe, O. Rascol, C. Sampaio, G.T. Stebbins, C. Counsell, N. Giladi, R.G. Holloway, C.G. Moore, G.K. Wenning, M.D. Yahr, L. Seidl, Movement Disorder Society Task Force Report on the Hoehn and Yahr Staging Scale: Status and Recommendations. The Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, *Mov Disord* 19 (2004) 1020-1028.
28. L. Kazis, J. Anderson, R. Meenan, Effect sizes for interpreting changes in health status, *Med Care* 27 Supplement (1989) S178-89.
29. C. Jenkinson, R. Fitzpatrick, J. Norquist, L. Findley, K. Hughes, Cross cultural validation of the Parkinson's Disease Questionnaire: Tests of data quality, score reliability, response rate and scaling assumptions in America, Canada, Japan, Italy and Spain, *J Clin Epidemiol.* 56 (2003) 843-847.

**Table Legends:**

Table 1: Descriptive statistics for 'early PD' respondents for which both the PDQ-39-SI and the PDQ-8-SI could be calculated at baseline and follow up at years one, two and three.

Table 2: Descriptive statistics for 'late PD' respondents for which both the PDQ-39-SI and the PDQ-8-SI could be calculated at baseline and follow up at years one, two and three.

Table 3: Mean (SD) median differences and effect size calculations for the PDQ-39-SI and PDQ-8-SI from baseline to years 1, 2 and 3.

Table 4: Hoehn and Yahr staging scale frequencies.

Table 1: Descriptive statistics for 'early PD' respondents for which both the PDQ-39-SI and the PDQ-8-SI could be calculated at baseline and follow up at years one, two and three.

	n	Mean	SD	Median	Min	25th percentile	75th percentile	Max
Baseline								
PDQ-39-SI	1434	23.69	21.22	21.22	0.00	12.70	32.20	80.63
PDQ-8-SI		24.53	16.95	21.87	0.00	12.50	34.38	84.38
Difference		-0.84	5.73	-0.44	-21.56	-4.34	2.97	16.98
Follow-up Year 1								
PDQ-39-SI	1237	25.28	16.07	22.34	0.00	12.63	34.66	82.19
PDQ-8 -SI		25.90	17.89	21.88	0.00	12.50	37.50	93.75
Difference		-0.62	5.00	-0.52	-27.29	-3.65	2.60	22.03
Follow-up Year 2								
PDQ-39-SI	1097	27.73	16.85	25.16	0.00	14.66	38.33	90.36
PDQ-8 -SI		28.83	18.97	25.00	0.00	12.50	40.63	100
Difference		-1.09	5.17	-0.83	-31.88	-4.17	2.14	16.04
Follow-up Year 3								
PDQ-39-SI	941	29.29	17.41	25.36	0.00	15.76	39.69	97.92
PDQ-8 -SI		30.38	19.57	25.00	0.00	15.63	43.75	100
Difference		-1.10	5.13	-0.78	-21.93	-4.22	2.31	14.48

Table 2: Descriptive statistics for 'late PD' respondents for which both the PDQ-39-SI and the PDQ-8-SI could be calculated at baseline and follow up at years one, two and three.

	n	Mean	SD	Median	Min	25th percentile	75th percentile	Max
Baseline								
PDQ-39-SI	433	23.57	14.05	21.98	0.00	12.53	31.22	81.72
PDQ-8-SI		24.26	16.83	21.88	0.00	10.94	34.38	84.38
Difference		-0.68	5.95	-0.21	--20.16	-3.84	2.97	17.50
Follow-up Year 1								
PDQ-39-SI	388	24.87	16.36	22.01	0.00	11.60	34.99	82.67
PDQ-8 -SI		25.28	18.28	21.88	0.00	12.50	34.76	90.63
Difference		-0.42	4.88	-0.03	-15.83	-3.68	2.86	15.36
Follow-up Year 2								
PDQ-39-SI	358	26.53	16.55	23.80	0.00	13.91	36.26	80.78
PDQ-8 -SI		27.39	18.41	25.00	0.00	12.50	37.50	84.38
Difference		-0.87	5.11	-0.76	-14.06	-4.39	2.63	17.40
Follow-up Year 3								
PDQ-39-SI	293	27.35	16.20	26.61	0.83	14.90	15.63	89.94
PDQ-8 -SI		28.62	18.59	28.13	0.00	36.46	40.63	93.75
Difference		-1.28	4.92	-0.94	-15.83	-4.32	2.08	10.94

Table 3: Mean (SD) median differences and effect size calculations for the PDQ-39-SI and PDQ-8-SI from baseline to years 1, 2 and 3.

	n	mean	(SD)	95% CI	Median	25 <sup>th</sup> percentile	75 <sup>th</sup> percentile	Effect size
Baseline-Year 1								
PDQ-39-SI	1459	1.99	(11.00)	1.42-2.73	1.51	-1.84	8.28	0.18
PDQ-8-SI		1.16	(12.84)	0.50-1.82	-1.35	-8.85	6.41	0.09
Baseline-Year 2								
PDQ-39-SI	1322	5.02	(15.15)	4.20-5.84	3.64	-11.41	2.51	0.33
PDQ-8-SI		4.77	(12.40)	4.10-5.44	3.13	-12.50	3.13	0.38
Baseline-Year 3								
PDQ-39-SI	1113	7.12	(13.35)	6.33-7.91	5.68	-14.30	1.54	0.53
PDQ-8-SI		7.55	(16.36)	6.59-8.51	6.25	-15.63	3.13	0.46

Table 4: Hoehn and Yahr staging scale frequencies

	1	1.5	2	2.5	3	4	5
Year 1	274 17.6%	222 14.4%	536 34.5%	258 16.6%	223 4.4%	33 2.1%	6 0.4%
Year 2	171 13.6%	161 12.8%	401 31.8%	243 19.3%	232 18.4%	41 3.3%	11 0.9%
Year 3	98 8.8%	134 12.0%	345 30.9%	212 19.0%	259 23.2%	56 5.0%	14 1.3%

**Highlights**

The PDQ-39 is the most widely used patient reported outcome measure (PRO) in trials for treatments in Parkinson's Disease.

A shorter form of the measure has been developed (the PDQ-8) which can provide the Summary Index of the parent form.

This study reports results from a longitudinal study that indicates the PDQ-8 Summary Index closely replicated results of the parent form.

This information is likely to be used for those planning to use the PDQ Summary Index as a primary or secondary in trials and other longitudinal studies.